

The Caregiver

Newsletter of the Duke Family Support Program

Volume 20: No. 2

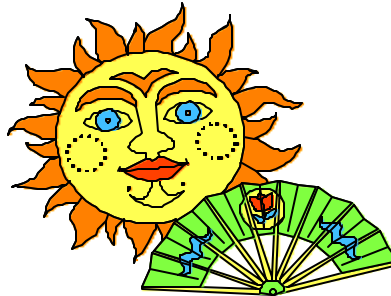
Summer 2001

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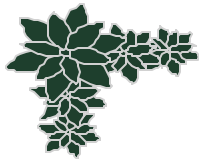
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**WANT TO KNOW MORE?
Find Almost 100 N.C. Family Support Groups**

Duke Family Support Program
Box 3600 Duke University Medical Center
Durham, NC 27710
1-800-672-4213 (NC only)
919-660-7510

Alzheimer's Association
Eastern North Carolina Chapter
400 Oberlin Road, Suite 208
Raleigh, NC 27605
919-832-3732
800-228-8738
Email: alz_east_nc@mindspring.com

Alzheimer's Association
Carolina Piedmont North Carolina Chapter
3420 Shamrock Drive
Charlotte, NC 28215
704-532-7392
800-888-6671
<http://www.perigee.net/~alz>

Alzheimer's Association
Western North Carolina Chapter
3 Louisiana Avenue
Asheville, NC 28806
828-254-7363
800-522-2451
<http://www.alz.org/wnc>

FOR OUTSIDE NORTH CAROLINA:
National Alzheimer's Association
919 N. Michigan Avenue, Suite 1000
Chicago, IL 60611-1676
312-335-8700
800-272-3900
<http://www.alz.org>

NORTH CAROLINA ALZHEIMER'S ASSOCIATION NEWS

EASTERN NC ALZHEIMER'S ASSOCIATION—August 14 & 21, 2001, Wilmington, NC and November 16 & 30, Fuquay-Varina--Professional Caregivers two-day workshop; October 6, 2001 – Memory Walk in Raleigh, (call (919) 832-3732 for satellite walk locations and times); September 7, 2001—Clergy and Community Workshop, Gates County; November 8-9, 2001, Annual Educational Conference, Chapel Hill (Friday Center).

NEW WESTERN CAROLINA CHAPTER EMERGES FROM WESTERN NORTH CAROLINA AND CAROLINA PIEDMONT CHAPTERS

WESTERN NEWS: Memory Walks will be held on September 22, 29, October 13, November 4th in various cities in NC (call 828-254-7363 for various satellite walk locations and times). **The Asheville office is in the process of hiring a family consultant** to improve the access, choice, use and quality of respite services in rural communities in Rutherford, Transylvania, Henderson and Polk counties and minority communities in Winston Salem. **Our annual Caregiver Education Conference, Customizing Care: Focusing on the Individual, will be held on November 7, 2001 at the Blue Ridge Assembly in Black Mountain.** Dr. Mark Pippenger, formerly from western North Carolina, and Lanier Cansler of the NC Department of Health and Human Services are scheduled as keynote speakers.





CAREGIVERS!!!!

(Disparity Among Us: Caregiving and Health)

By: Juliessa M. Pavon, Duke Family Support Program Gabel Leadership in Aging Society Intern

(I'm Always in Parentheses)

(I'm always in parentheses)
(which makes me hard to hear)
(regardless if I'm yelling loud)
(or if you're leaning near.)

(It sounds as if I'm whispering)
(my voice is just a squeek)
(and even if I scream and shout)
(it comes out soft and meek.)

(Parentheses imprison me)
(they hold me like a jail.)
(I try to break these tiny curves)
(but every time I fail.)

(I'm sick of these parentheses.)
(these little muffling arcs.)
**I WISH I WAS IN
CAPITALS WITH
EXCLAMATION
MARKS!!!!**

-Ken Nesbitt

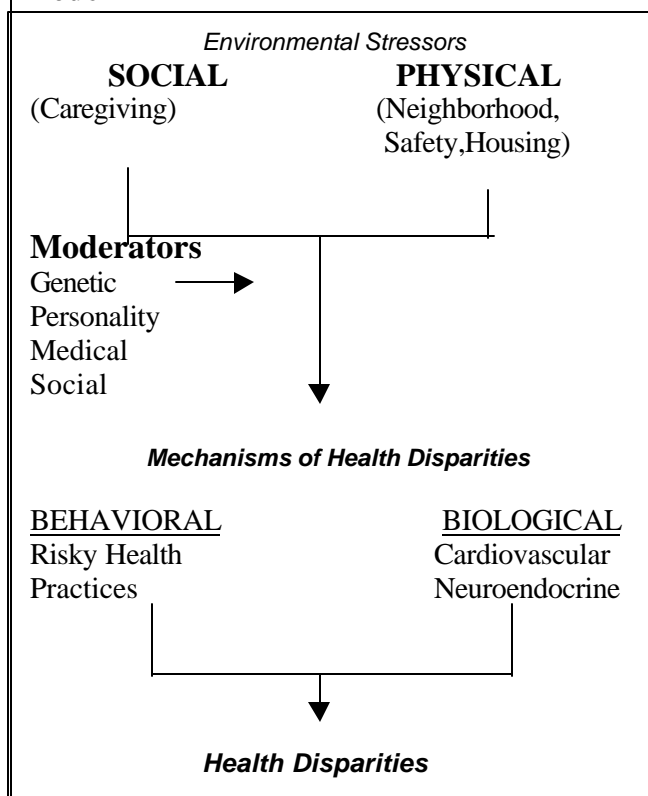
As a spouse of someone with dementia, one often feels surrounded by stress. Have you ever wondered what specific aspects of your life contribute to this stress? At first, the answer may seem simple—lack of time, lack of support, too many demands, too much to think about. What if there is a more significant question to ask? How do you respond to stress? This question highlights two crucial points: 1) People respond to stress in different ways, and 2) The way one responds to stress can influence future health outcomes. Stress, unfortunately like the parentheses, may make it difficult to hear and meet the needs of your impaired spouse. Stress can also imprison you, especially when your health is at risk. A new research study is ready to address the loud impact that stress has in the lives of SPOUSE CAREGIVERS!!! (Let's make sure these different impacts of stress do not remain silent or potentially harmful.)

On May 30th, ten multidisciplinary teams of national researchers, among them Duke University Medical Center researchers, joined forces in tackling one of science and medicine's highest priorities: understanding health differences among individuals and groups at risk. The twelve "Health Disparities" research grantees of the National Institute of Environmental Health Sciences come from leading academic research centers. They are investigating a wide range of biological and behavioral risk factors that lead to differences in health, illness, and even death among individuals and groups, from prenatal development through late-life. Examples of "at risk" groups for health disparities are people with Alzheimer's and their families, children with asthma, North Carolina female poultry workers, and the older people in urban areas.

The Duke research team, led by Dr. Redford Williams, Director of Duke's Behavioral Medicine Research Center, will conduct a five-year in-depth investigation of

husbands and wives caring for spouses with Alzheimer's or other dementia at home or in nursing facilities in **CENTRAL NORTH CAROLINA**. Caring for and about a spouse with a memory disorder is considered a social stressor with physical, psychological, and social consequences. The project is titled **"Caregiver Stress, Health and Serotonin Genes"**, and recruitment of 200 spousal caregivers and 200 spouses of persons without dementia is underway. The Duke research team hopes to identify how genetics, personality type, medical history, physical environment, and social support affect biological and behavioral responses to stress. In so doing, they hope to gain further understanding of how behavior and health practices, genetic susceptibility, biological (cardiovascular) characteristics, and race and gender, possibly contribute to differences in the course of major diseases among individuals caring for a spouse with dementia. The next step is to identify caregivers who are most at risk from negative effects of chronic stress

Model



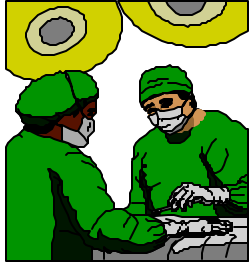
Different health outcomes, yet a similar experience: CAREGIVING!!!

in order to develop programs to prevent these bad health outcomes. The effort to address both social as well as the environmental components of stress is unique. Researchers plan to document in detail the environmental stressors present in each caregiver's neighborhood, in addition to collecting information on the stress involved in actual caregiving. Gathering such information will lead to an understanding of the interaction between biology and the environment in response to stress. This interaction may be a strong predictor of how stress is handled differently among caregivers, and ultimately a predictor of the risk of major diseases as a health outcome of caregiving.

Alzheimer's caregivers were chosen for this study because previous research indicates that the loss of support from a spouse who has Alzheimer's disease, along with the chronic physical, emotional, and financial demands of caregiving, put older spouse caregivers in a population that is at an increased risk of health problems. This is an increasing group of individuals with unmet or poorly met needs, and these needs are driving a search for answers.

TRANSLATION OF FINDINGS FOR COMMUNITIES AND PRACTICE

A major component of these projects is the effort to continuously report research findings to affected caregivers, and to use findings to inform public health policy. Director of the Duke Family Support Program, Lisa Gwyther, MSW, will lead the initiative to translate findings about health disparities among caregivers through a Community Outreach and Education Program (COEP). This program will provide a new form of communication and a continual source of resources and services to research participants and their communities. The COEP addition to the enterprise responds to community concerns, and above all, translates basic research into improved health outcomes. For more information, call Lisa Gwyther or Edna Ballard (in NC only) at 800-672-4213 or email lpg@geri.duke.edu



Long-term Cognitive Declines after Bypass Surgery

Excerpts: *DukeMed* 1 (1):19 Summer 2001

Editor's Note: In response to several recent questions about the effects of bypass surgery on thinking and memory, we offer this recent synopsis.

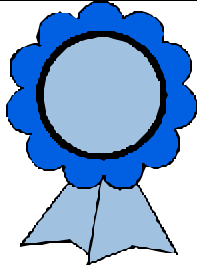
“The key finding (of a Duke prospective trial) was that acute cognitive dysfunction occurring after bypass surgery predicted long-term cognitive decline at five years” said Mark Newman, MD, the lead author of an article in the February 8, 2001 issue of *The New England Journal of Medicine*.

Five years after surgery, one-third of patients will have measurable cognitive decline, although many bypass patients exhibit some cognitive defects shortly after surgery and improve over months. 261 patients were given cognitive tests before surgery, seven days after surgery, at six weeks, six months and five years. 172 patients completed all five tests. At 7 days, 53% had a cognitive decline but by six months, 24% had cognitive decline. However, at five years, 42% had cognitive decline. Cognitive decline at five years following bypass surgery was predicted by cognitive decline at discharge, older age, and level of education. These study participants who declined showed a decline more than two times that demonstrated by 5,888 Medicare patients in a recent five-year study.

A new international research program based at Duke and led by Dr. Newman aims to improve outcomes for many patients who face substantial declines in cognitive function and quality of life after any type of surgery. The International Anesthesia Research Society in partnership with Duke Clinical Research Institute will design and conduct clinical trials focused on the time a patient is admitted to the hospital through the time of discharge. The findings from these trials could be very important to any older person facing surgery. Stay tuned.

MORE NATIONAL ATTENTION

Duke's Department of Psychiatry and Behavioral Science ranked 7th in the *U.S. News and World Report*. “Best Hospitals” report from July, 2001.



Family Caregiving: “Good Enough For Now”

-Cornelia M. Poer, MSW and Edna L. Ballard, MSW

“...No caregiver arrives at the same conclusion in the same order or for the same reasons that I have, just as no individual assembles a jigsaw puzzle in the same sequence, even if all the pieces are the same.”

---Elizabeth Czeck Beckerman
Chapel Hill, North Carolina

Caregiving has many rewards. It is also an awesome responsibility that can be physically and emotionally exhausting. There are occasions for anger, fear, sadness, and the desire to be free of caregiving responsibilities. Many things about caregiving cannot be changed—the course of an incurable disease, the irascibility of a dependent parent or the lack of sufficient funds when one has to give up his or her employment for caregiving. Adapting the attitude, “*good enough for now*”, allows you to be more flexible and reasonable in your expectations of yourself. You can do the best you can at the moment with the time, energy, and resources available to you without recrimination, regret, or second guessing. Changing those things you can change and accepting those you cannot offer the most balanced approach to caregiving.

Give Yourself Permission to be Imperfect

- You do not have to be strong and correct at all times. Nobody was born an expert. “Great caregivers are made, not born.” Great doctors, social workers, nurses, and caregivers became great with practice.
- Don’t demand more of yourself. You become good or proficient one lesson at a time, sometimes after repeating a lesson over and over until you get it right. Mary W. writes in *Lessons Learned*, (Ballard, E.L. & Poer, C.M. (2000) *Lessons Learned: Shared Experiences in Coping* from the Duke Family Support Program). “I cried for a year or more—gained 20 pounds from worrying and eating....Cried some more and it went on and on...Then I began to see...little things weren’t BIG anymore. And life went on.”

Know that Caregiving is Difficult

- Generally in life, the more experience you have with doing something, the better you get at doing it and the “easier” it becomes. If you knew that every day would be just like today, you could learn to manage the task of caregiving, no matter what the challenge. Unfortunately, taking care of someone with dementia becomes more challenging as time goes by—from day to day and even from hour to hour within the day.
- It is OK to expect help. Often, we are our own worst critics and expect more of ourselves than is reasonable or possible.
- It is OK to ask for help. Needing help is not a character flaw.

Do Your Best

- Do your best under the circumstances. These are circumstances you did not create and which are beyond your control. *"You cannot control the wind but you can adjust your sails."* This is wisdom of the ages. Our grandfather would say—"roll with the punches," our children would say—"go with the flow," and your minister or therapist might say—"it's finding balance in your life."
- Doing your best does not mean committing yourself to the point of physical, emotional, and financial exhaustion, even when you feel no one can do the job as well as you can. Doing your best requires seeing that the person gets the help he or she needs. It does not mean that you alone should do it. It means accepting "good enough for now" solutions.

Accept the Reality of What *is* in Your Life

- In social work, we "meet the person where he/she is." Learning to "meet" our loved ones and ourselves where we are can be key to compassionate caregiving.
- Appreciate and encourage remaining abilities. While short-term memory and details may be lost, long term memory of the essence of things is often quite intact. Reminiscing about the past can be very rewarding and enriching to the person with memory loss as well as family members. Talking about past successes and joys may promote feelings of self worth. Other hidden or underused skills and interests may remain such as artistic talents, humor, or athletic abilities. Exploring and appreciating remaining abilities may go a long way in accepting the reality of what *is*.
- Enjoy the person as she or he is today. We are always changing. If you are married, your spouse is different today than on your wedding day. And so are you. Careers, children, and life experiences are constantly changing who we are. We may embrace some changes and reject others, but we have learned to accommodate to changes in others and ourselves. Dementia, by definition, is a change in memory and thinking significant enough to impair activities of daily living. It is a given that dementia will change our loved ones and ourselves. By using our fine-tuned skills for adjusting to change, we can look for the best, the embraceable changes and enjoy our loved ones for the people they are today.

Conserve Time and Energy

- A caregiver writes that caregiving is "a rocky road of fatigue, frustration, loneliness, increased responsibilities, decreased affections and companionship..."
- Conserve time and energy by learning techniques for managing special needs or concerns of the ill person.
- Hire yard help, use pharmacies that deliver, plan your errands so that you can do everything on the same side of town, keep a list of helpful hints which appeal to you, i.e., keeping the dry cleaners' slip in your automobile glove compartment so it's always available.
- Use the help of experts (professionals, books, tapes, classes, support groups, etc.). Take a class on how to make a bed with the person in it from the local Red Cross or health department or use, for example, the Non-Chew Cookbook, in preparing meals for someone who has difficulty chewing or swallowing. Make multiple meals and freeze several for later use.

Economize Emotions

- Don't sweat the small stuff—If you "sweat the small stuff" you are not alone. Richard Carlson wrote a popular series of books called "Don't Sweat the Small Stuff." We are most likely to sweat the small stuff when we feel our lives are out of control. Initially, we may search for the little things we can control because our lives and the situation may feel so completely out of control. Before we know it, we have gotten mired in the minutia of small stuff.
- "Small stuff" is different things to different people. If you are sweating the small stuff, ask yourself "why?". "Do I feel out of control?" "Am I stuck?" Then begin to make appropriate changes.

Take Care of Yourself

- Exercise, eat well, sleep and make time for your own needs. Do those things that will renew and restore you. If family caregivers ignore these normal human needs, they are at risk mentally, physically and spiritually. When resources are drained, there are fewer opportunities for respite or support. Simple exercise, for example, has many benefits including: you can do it anytime, as much or as little as you have time for, and it can be tailored to your particular need or style. It can be informal or designed by your physician or physical therapist to meet specific needs. It is the rare person who cannot benefit from some form of exercise.
- Make time for yourself. A spouse writes: *"My body was tired. I did not sleep well. I could not think clearly when I had to. And my anger increased. I was a rubber band stretched to my limit and I felt emotionally bankrupt."* Self-care is especially important when care efforts deplete the caregiver, or when the dependent person cannot say 'thank you', gives little in return, or actively resists needed assistance.

Learn from Others

- More than fifteen years ago, an experienced family caregiver, Leonell Robeson from Statesville, instructing other caregivers had this advice: *"Get a sitter and get out—lunch with a friend, a movie, shopping or, as one day last week, I went to the church library and spent three hours in peace and quiet to catch up on some paperwork...Go clothes shopping—I have spent more on clothes than ever before in my life but not to extravagance. I tell myself, 'I deserve it!'"* One of the greatest tension relievers for me is water exercise and swimming (though I am not a good swimmer)...*One day he started hallucinating so I couldn't leave him again. But this is so important to my well-being that I have finally located a service that provides a trained attendant to come in three mornings a week. . . .While I can't afford it often enough, occasionally I make good provisions for him and I get away for a few days. I know I am a good care provider and that he possibly feels more secure with me—but I know to maintain my sanity I have to completely remove myself from the situation. I don't worry about him while I am away, and I don't feel guilty about leaving him. Some days caregiving is challenging; some days a 'drag,' but when I begin feeling sorry for myself, I start planning a diversion. It keeps me functioning and it makes me proud of myself. I can accept the fact that I am not superwoman."* All these years later this advice is still good, still as fresh as when it was first offered by this wonderfully balanced caregiver.

Accept Help from Others

- Here is the hardest part for some people. We are a society that values independence. Is asking for help really a sign of weakness? Many of us have never asked for help. We don't know how. Others asked and didn't get the help they needed so they stopped asking. Some of us have "our noses on the tree" and don't even realize we need help.
- We have to give ourselves permission to ask for help and accept it. Without this step, feelings of inadequacy and guilt can come up and keep us from getting help in the future. Many people are very willing to help if we only allow them to do so. Often friends and family are afraid to "step on toes" and will tell you to call them if you need help. Calling to ask for help can feel like an additional burden and may leave the caregiver wondering if "I should just do it myself."
- First you must identify the help you need. As you go about day to day tasks, make a list of areas where you could use help. When you decide to ask for help or someone offers to help, have a clear idea of what you want. The "helper" also has a clear idea of what you need, and whether he/she can or cannot do it. Don't give away tasks that you enjoy.

Forgive Yourself When Plans and Efforts Go Awry

- There is no game plan. Most success comes through trial and error. What works perfectly today may not work tomorrow. It's like playing a game where the rules are always changing. We learn as we go. Even when you are experienced, even when you know a lot about the disease and how it affects the person, no caregiver can muster what it takes to remain patient and calm all the time.

Sometimes you will lose your patience, yell or cry, or say things you later regret. What is important is the next step—how you pick yourself up and go from there.

- The Reverend Tanya Vonnegut Beck writes in *Daughters of the Elderly: Building Partnerships in Caregiving*, (1988). “Of all the inner transactions, forgiveness may be the most difficult. It means letting go, taking new risks, and sometimes forcing painful confrontations with yourself and with others.” We must be willing to take the risks.
- Learn from your mistakes: There are no perfect solutions. No supermen. No saints.
- Not being able to move on, especially from painful situations or memories, results in missed opportunities. Moving on means having confidence that the tools you have for the task are the best available to you. Moving on means being aware that the road ahead will not necessarily be straight. There may be bumps and bends in the road, unexpected barriers, the need to make new decisions, the need to get more instructions, guidance or support along the way. Moving on, most importantly, means that you did the best you could under the circumstances with what you had. It means applauding and appreciating yourself, even when you didn’t do everything perfectly.

Remember You Can Say, “No”

- You may have to practice saying “no” and standing up for yourself and your family member. Even if you do say “no”, others may not be listening. Stand your ground. Don’t give in, if at all possible. You can say “no” in a kind way without alienating others.
- Caregiving is not for everyone. Most people are not born with the skills necessary to provide care 24 hours per day for prolonged periods of time. Sometimes unresolved issues or “ghosts” from our past make family care impossible. Assuming the role of care manager may make more sense. Becoming the “chairperson of the board” can ensure your loved ones’ needs are still met.
- Even if you have the desire and ability to provide the care your loved one needs, often other demands keep you from assuming responsibility for care. Spouses, children, distance and careers are just a few of the other responsibilities you may have.

When to Choose the Role of Care Manager

- There may be a number of reasons why you cannot take on the role of “caregiver”: distance, family or work obligations, your health status, relationship history with the care recipient, temperament. The role of “care manager” is a more viable option when you do not wish to be intimately involved in personal care.
- See yourself as the Chairperson of the Caregiving Committee. Bring to the table past skills to structure care routines. Delegate tasks and responsibilities much the way you would in a corporation with the same expectations that the whole will benefit from the contribution of many (skills, time, commitment, different ideas and perspectives).

Know Which Battle to Fight

- This may save your sanity. As long as the safety of your loved one and others is not in jeopardy, let things go. Say or think “let it go” or “Throw it into neutral.” These phrases will do wonders in defusing situations. Trying to make someone who cannot remember and may lack judgment understand becomes an exercise in futility. If your loved one is in a care facility, choose your battles even more carefully. If you confront staff on every issue, they soon tune you out and nothing you say has any value. The same can be said about other family members. They may not provide care the same way you would, but picking every situation apart will have the opposite effect. You will have more than ample opportunity to do it your way because you will be left holding the bag.

Set Priorities: These Simple Questions May Help Set Priorities

- What are the most urgent needs of the care receiver? Caregiver? Other family members?
- What are the consequences if I ignore a particular “issue” or “problem”?
- Am I the only one who can do this? Are there others available who are willing to help?
- What can I delegate to other people?

- Is this something that must be done now?
- Who will be affected by the decisions that I make?
- Why am I doing this –habit, tradition, someone else’s expectation, guilt, comfort, fear of reprisal or objection from the care receiver?
- Have I paid attention to the emotional needs of all involved?

Get Help

- You cannot do this alone.
- Sometimes the biggest barrier to getting help is finding it. You must know what help you need and are willing to accept before you begin looking. You may have to start big, such as the Area Agency on Aging or Council on Aging, to determine what type of services are out there. You may have to start small and make a list of the tasks and then look for assistance. Just saying you need help is not clear enough. Be specific. “Someone to sit with Dad every Thursday afternoon from 3-5 during my pottery class.” “Someone to cut the lawn once a week.” Most communities have access to home health care. Some have Senior Centers or congregate meal sites. Adult day programs or assisted living may be what you need. Support groups are great places to ask about local help. Thinking “outside the box” may also open up opportunities. If finances are limited, it still may be worth your while to purchase what services you can. You may be able to manage the day-to-day responsibilities of caregiving, but feel overwhelmed with the additional demands that come along. Necessities such as taxes, bill paying, yard work, grocery shopping may become insurmountable problems if you must insure 24-hour supervision. Hire out or “out-source” the services you do not or cannot provide. Again, spending money now may save money in the long run.

Take One Day At a Time, But Prepare for the Future

- Learn to focus on the moment. Focusing on the moment allows you 1) to be completely “present” with the person and his or her disability, 2) to fully appreciate the person and what they can bring to the relationship despite his or her disability, and finally 3) it allows you to see more clearly and do the task at hand well. Your family member’s condition will change. Focusing on today does not mean you are neglecting or ignoring the future.
- Changes may necessitate moves. Do you need a living will, durable power-of-attorney, family conference? Putting your plans, needs, and desires in writing is critical. Writing down and distributing copies of what you would like to have happen or what you have already arranged is crucial.

Establish a Contingency Plan

- A contingency plan can make the difference between a crisis and a stressful situation. Evaluating helpers and making decisions under less pressure is better for all involved. This also provides adequate time to investigate additional resources or track down needed information.
- Even the best plans or situations can get off track without notice. Know what you want in advance and how to go about getting it. Gather information or make arrangements now to save time and money later.
- All the work in the world will be useless if you are not available to explain or implement it at the time it is needed. Put your plans, needs, and preferences in writing. Write down what you would like to have happen or what you have already arranged. Remember when it comes to caregiving, “*Good Enough for Now*” may be just right.



There are many “tools of caregiving.” This simple “on-call” calendar is one of many examples you may choose and adapt for your own use.

When my father became ill, we developed an “on call” schedule for my mom. My mother taught ceramic classes two nights a week. There are five children in the family. Three of us lived within 15 miles of our parents and the other two lived a great distance away. There were times when we changed the “on call” days with one another or filled in for one another for vacations. Having a schedule and knowing that someone was available provided my mom with support and the security that she was not alone. Whoever was scheduled on a class night stayed with dad during that time. This was a wonderful opportunity for one-to-one time between father and child.

AUGUST 2001

Sun	Mon	Tues	Wed	Thur	Fri	Sat
			1	2	3	4
			Charlie	Nell	Betty	Charlie
5	6	7	8	9	10	11
Nell	Betty	Charlie	Nell	Betty	Charlie	Nell
12	13	14	15	16	17	18
Betty	Charlie	Nell	Betty	Charlie	Nell	Betty
19	20	21	22	23	24	25
Charlie	Nell	Betty	Charlie	Nell	Betty	Charlie
26	27	28	29	30	31	
Nell	Betty	Charlie	Nell	Betty	Charlie	

Submitted by: Mrs. Nell Causby, Morganton, NC



Teamwork divides the tasks and multiplies the success.

-Unknown

Negotiation

The fellow who says he'll meet you halfway usually thinks he is standing on the dividing line.

-Orlando A. Battista



SAVE THESE DATES

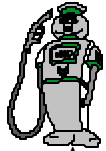
**The Sixteenth Annual Joseph and Kathleen Bryan
Alzheimer's Disease Research Center Conference**

**ALZHEIMER'S 2002: WHAT'S NEW AND
WHAT'S TRUE?**

February 7-8, 2002

Durham Marriott at the Civic Center

**For registration and information call (919) 660-7510 or
(800) 672-4213 in NC or email jardi001@mc.duke.edu**



“CAREGIVER ALTERNATIVES TO RUNNING ON EMPTY”

An Administration on Aging Alzheimer’s Disease Demonstration Grant was awarded to the North Carolina Division of Aging for Project CARE (Caregiver Alternatives to Running on Empty). North Carolina was one of nine states funded for three years to develop innovative models for better serving Alzheimer’s families at the local level.

Project CARE’s focus is to improve access, choice, use and quality of respite services. This will be accomplished by providing a family consultant service that will assist caregivers in finding and funding consumer-directed respite care in targeted rural and minority areas.

North Carolina’s Division of Aging will partner with the Western Carolina Alzheimer’s Chapter, Duke Family Support Program, four Area Agencies on Aging and churches in three targeted areas. These areas include the urban African-American community in Winston Salem, and rural mountain communities in Polk, Rutherford, Henderson and Transylvania counties and for study comparison, Mecklenburg County.

The federal grant award is \$350,000 a year for a three-year period. The first year total budget, that includes a 25% match, is \$466,667. Of that amount, \$233,400 (50%) is funding for respite service. Total federal funding for the three-year period is \$1,050,000 (64%). Total non-federal match is \$591,493 (36%).

For more information, contact Project Director, Jan Moxley at 919-733-0440 or the Duke Family Support Program at (800) 672-4213.



DUKE FAMILY SUPPORT PROGRAM NEWS

Thank you, Juliessa

Juliessa Pavon, a Duke senior Psychology/pre-med major, is completing a Gabel Leadership in Aging Society internship with the Duke Family Support Program. This internship is funded by a family foundation with a special interest in Alzheimer’s care. Juliessa concentrated her time on the spousal caregiver study that she describes in this issue. She also prepared a caregiver web resource guide for a primary care psychiatry journal, assisted with presentations for the NC Family Caregiver Support Program, and she even developed original materials for a Durham Alzheimer’s Association support group topical discussion. (See sample of her poetry in this issue as well). Juliessa intends to complete a senior honors research thesis on Alzheimer’s, and has already expressed a genuine interest in a career in geriatric medicine. She has even offered to continue as a volunteer with the Family Support Program through her senior year. Now that’s enthusiasm!

Caring for People with Alzheimer’s Disease: A manual for facility staff

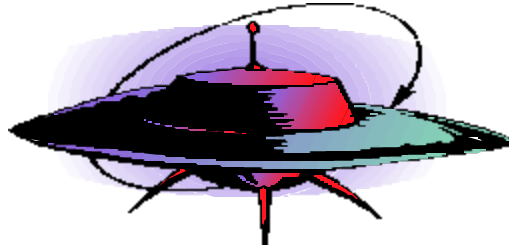
The second edition of Lisa Gwyther’s popular paperback on caring for facility residents with Alzheimer’s disease was jointly published in May, 2001, by the national Alzheimer’s Association and the American Health Care Association. (See ordering information under “Have You Heard About?”). This 1985 paperback has been substantially revised with new stories and tips focused on behavioral symptoms, activities, environment and communication. The publishers anticipate this book will be a favorite with families as well as facility staff.

No Batteries Or Memory Required

By Tim Brennan--Sterling, Michigan

“We must be willing to get rid of the life we’ve planned, so as to have the life that is waiting for us.”

--Joseph Campbell



Often, when people with Early Stage Alzheimer’s Disease meet, the central topic of our discussion is difficulties with memory, particularly short term memory loss. We give it top billing, the numero uno problem we endure.

And yet, today, as I think about memory, I wonder if this opinion is correct?

Our loved ones will remember for us. Granted, their view, their observation of whatever transpired will differ from our own, but how important is this difference?

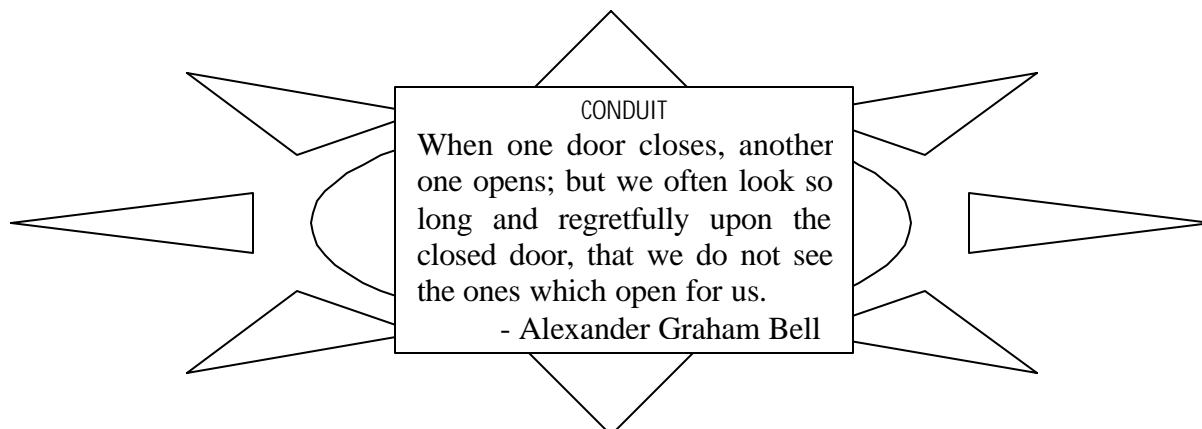
The finest statement, the greatest honor, one can ever give to another is to do something we did or would have done. It is to almost live on, beyond death, in some hopefully beneficial habit ingrained in our children or grandchildren.

Therefore, I am more inclined to believe that if I try to concentrate on doing something today in a positive constructive manner, while attempting to minimize or downplay the effects of memory loss, it will lead me to try to make tomorrow even better. Perhaps, in time, a new and improved version of me will emerge and my loved ones and I will both adapt and gain from this change.

An honest, quiet, introspective moment, alone with “self” strips away the veneer of everyday living. The stark view – the reality of who and what we truly are, provides us with the opportunity to envision who and what we can be. The framework of the doorway leading to a potentially better tomorrow must be constructed from what is present today.

Today is a building block which uses yesterday as its foundation. And, tomorrow will be built upon what we do or have done today.

No tools are necessary. Assembly is simple. No batteries or memory required.





WALK IN THROUGH THE DOOR

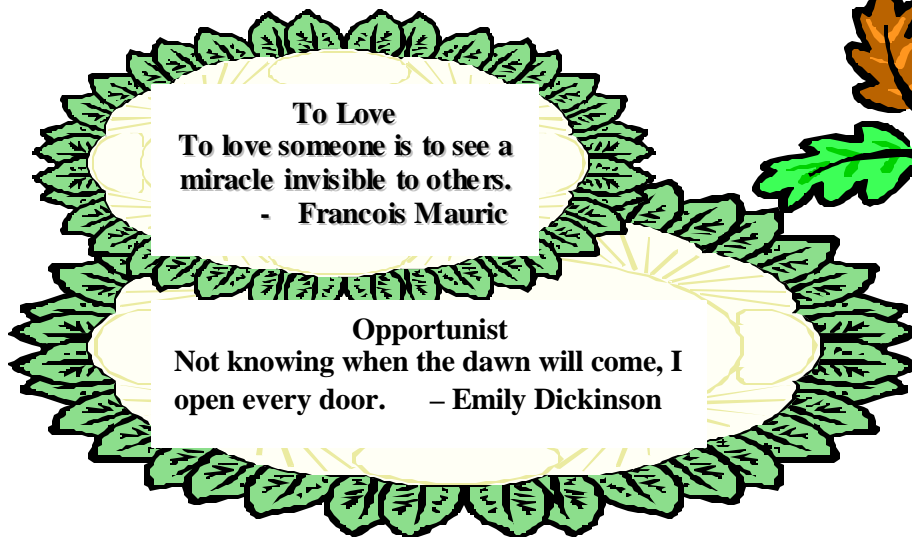
The nursing home: I see you walk in through the door
An environment I have grown to know more
Do not be afraid, for I travel with you
Let us hope together, for our goals will become true.
Take me to the patio, let me see the sunshine of your smile.

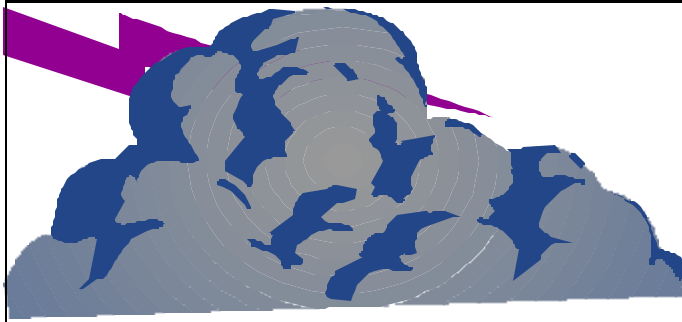
The nursing home: I see you walk in through the door
Talk to me so that I may hear you
Wave to me so that I may see you
Touch my hand so that I may feel you
You laughed with me when I needed to laugh.

The nursing home: I see you walk in through the door
In this nursing home, together we will mesmerize the world, the world that is truly my own
world.
Learn the song that is in my heart
And sing to me when I have forgotten.

The nursing home: I see you walk out through the door.
But you came, and you sang to me
And that has made all the difference.

-Juliessa M. Pavon





Grandmother

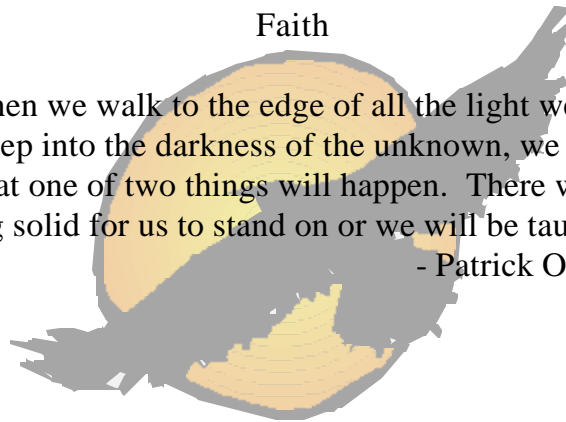
by Milton Dail, Washington, NC

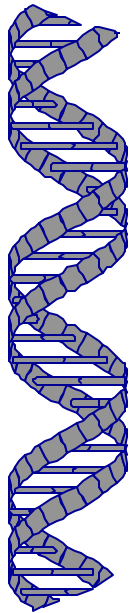
There you are high on a cliff
With a blackberry cloud between us
The whirring winds keep us from talking
And sadness pricks our hearts like needles.
My mother and I have often cried about your fate,
But now, it is just too late.
The terrible villain you battled for years has finally won.
Oh, how I wish there was a cure
For this dark disease of the living dead.

Faith

When we walk to the edge of all the light we have and
take the step into the darkness of the unknown, we must
believe that one of two things will happen. There will be
something solid for us to stand on or we will be taught to fly.

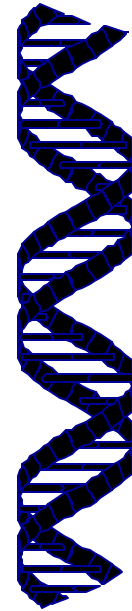
- Patrick Overton





The Inheritance

By Patricia Bondor



“Could you please fill out this form? We are updating our records,” a baby (pretending to be a medical receptionist) asks me as she shoves a clipboard and pen towards me. I’m here for a physical. I hate these forms for the doctor. I really hate answering the same questions about the diseases in my family: Diabetes? Cancer? Heart Disease? I check practically all the boxes. Can’t be certain. I think old Uncle Sam died with some kind of cancer. What diseases are hiding in my genes? My dad had Alzheimer’s. Will I get it? My mind wanders at the possibilities of my future health. How well will I age?

A strange thing is happening in my family. My children have started discussing their options regarding my placement in a nursing home and occasionally asking me “When you die, can I have this?” I’m sure you’re thinking there’s nothing odd about that. I assure you, there is. My children’s ages are 14 and 21. I’m not even officially middle-aged and my children are questioning me about life insurance. They’ve started discussing who gets what in the house. They are even dividing the inheritance I’ll get from my mother!

As an “almost” middle-age parent, I have started to think about what I will leave behind for my children. I keep telling them I plan to go out just like I came into this world: with a net worth of \$0. They aren’t especially pleased with that prospect. Truthfully though, of course I’ve purchased life insurance and I started working on a will. I get regular medical checkups, and exercise (sort of!). I’m trying to plan for my retirement and my children’s college education. I’m trying to think of everything, just like my parents did.

My father was a career military man. . .an officer, veteran of three wars. He learned to plan for all situations, and to be ready to handle anything at a moment’s notice. One thing he didn’t know he was planning for was dealing with Alzheimer’s disease. When he died 15 years ago, he was 57. The medical field was just learning about this disease; most of the public knew nothing of it. There were no “nursing home Alzheimer’s units”. The VA wouldn’t/couldn’t take him or deal with his disease. My mother spent everything my father had saved to pay for his care. We are all grateful we had it to spend on him. The inheritance my father worked so hard to leave us is gone.


My father left us with a different inheritance. An inheritance that’s more valuable than money. He left us his DNA. This valuable information will be passed along to my children and their children. The information it contains will be available for whatever medical advances to treat or even prevent genetically inherited diseases. When my father died at such a young age, an autopsy revealed that he probably had AD in his early 40s. The doctors told my siblings and me that we were likely to inherit the disease. Today, research suggests that it may be even more

complex than that. As we learn more about a disease, treatments can be targeted to specific causes. By the time my grandchildren enter this world, they may even have prevention and delay strategies. Knowing their genetic history will be critical. DNA retrieval and storage is not the type of inheritance we think of leaving. I have already passed along the genetic markers. Now I just need to leave them the map that will lead to the real treasure chest.



Involvement












Your sole contribution to the sum of things is yourself.
- Frank Crane



Generosity

Real generosity toward the future lies in giving all to the present.
- Albert Camus

DID YOU KNOW THAT EXERCISE:

-  Helps you effectively manage stress?
-  Increases the density and strength of bones?
-  Increases circulating levels of good cholesterol?
-  Reduces anxiety?
-  Boosts creativity?
-  Improves balance and coordination?
-  Reduces your risk of developing Type 2 diabetes?
-  Helps you sleep?
-  Helps alleviate depression?
-  Improves brain function?
-  Helps control blood pressure in people with hypertension?

From Wellness Works at Duke, June, 2001



Have You Heard About?

Achieving and Maintaining Cognitive Vitality with Aging: A Workshop Report. (2001). Free single copies from www.aging-institute.org. (212) 572-4086.

Georgia Law Review. 35 (2) Winter 2001. Symposium: Joint Conference on Legal/Ethical Issues in the Progression of Dementia.

Goldfein, Susan. (2001). Conversations. An interactive photo and story album designed to help create the reader's life story. To order: Ideas 'R' Popping (203-221-7917, fax: 203-386-0291 or email: info@ideas'r'poppin.com. \$8.95.

Gwyther, LP. (2001). Caring for People with Alzheimer's Disease: A Manual for Facility Staff. Publishers: Alzheimer's Association and the American Health Care Association (AHCA). A helpful guide for frontline facility staff and families. To order: (800) 272-3900 or (800) 223-4405, fax (877) 356-9119, email: alz@pbd.com or buy it directly from your Alzheimer's Association chapter.

Harper, MA. (2001). The Worst Day of My Life, So Far: My Mother, Alzheimer's and Me. **A novel** Athens, GA: Hill Street Press. \$24.00/hardback.

Inside Grief. (2001) \$20.00 with shipping. Checks to: Wise Press, PO Box 180928, Coronado, CA 92178 or online purchase at www.wisepress.com.

Kondracke, M. (2001) Saving Milly: Love, Politics and Parkinson's Disease. New York: Public Affairs. \$25.00 hardback.

Langdon, Mary Janine. (1998) When Meme Came to Live at My House. A book for children through age 10 about living with a grandparent with memory loss. Illustrated by Adam Padilla. \$5.00 with shipping but bulk discounts available. Sample pages and ordering information from www.memeandme.com.

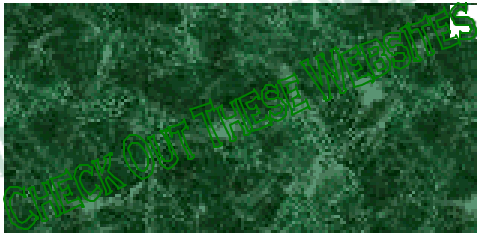
Progress Report on Alzheimer's Disease, 2000. <http://www.alzheimers.org>. Free printed copies: (800)438-4380, fax 301-495-3334 or write ADEAR, PO Box 8250, Silver Spring, MD 20907-8250.

Silin, Peter S. (2001) Nursing Homes: The Family's Journey. The Johns Hopkins University Press, 2715 N Charles St., Baltimore, MD 21218-4319. www.jhupbooks.com. ISBN#: 0-8018-6625-1, \$16.95/paperback.

Talking With Your Doctor: A Guide For Older People . This is easy to read and newly revised. National Institute on Aging. For single, free copies call NIA Information Center, 1-800-222-2225.

The Lost Art of Caring: A Challenge to Health Professionals, Families, Communities, and Society. (2001) Edited by LE Cluff, MD and RH Binstock, Ph.D., The Johns Hopkins University Press, 2715 N Charles St., Baltimore, MD 21218-4319. ISBN# 0-8018-6591-3. \$48.00/hardcover. See chapters by Callahan, George and Stone.

Working Through Grief: Self-Care Handbook. (2001). Deerfield, MA: Channing L. Bete. 800-628-7733 or email custsucs@channing-bete.com. Bulk discounts available.



<http://seniorcareweb.com/senior/> -comprehensive caregiving and eldercare info.

www.aoa.gov/carenetwork. National Family Caregiver Support program information.

www.alzstore.com Products for home safety and care from the author of *Alzheimer's-Proofing your Home*.

www.dasn.org A unique online chat room for individuals with memory disorders.

www.benefitscheckup.com. New National Council on Aging site. Fill out a confidential questionnaire to receive details about an elder's eligibility for financial assistance, nutrition programs and prescription drug assistance.

www.ec-online.net. Elder Care online. "Tell me why—show me how—hold my hand" logo does just that.

www.carethere.com. Caregiver marketplace of services, caregiver guides and answers to medication questions.

www.caregiverzone.com. Caregiver 101 section and a nationwide database on elder care resources.

www.alz.org. National Alzheimer's Association—See new facts sheet on Vitamin E and Statins.

www.medicine.mc.duke.edu/ADRC. See current research and Duke Family Support Program materials from Duke's Bryan Alzheimer's Disease Research Center.

www.dhhs.state.nc.us/aging/home/htm. NC Division of Aging offers comprehensive listing of services and programs throughout NC.

www.parkinsons-care.com. In-depth information on caring for persons with Parkinson's Disease.

www.findingourway.net. Living and Dying in America. A 15 part newspaper series running August 6-December 17, 2001 in Knight/Ridder newspapers on end of life care, family care, grief and bereavement.

www.nfcacares.org. National Family Caregivers Association.

Joseph and Kathleen Bryan Alzheimer's Disease Research Center



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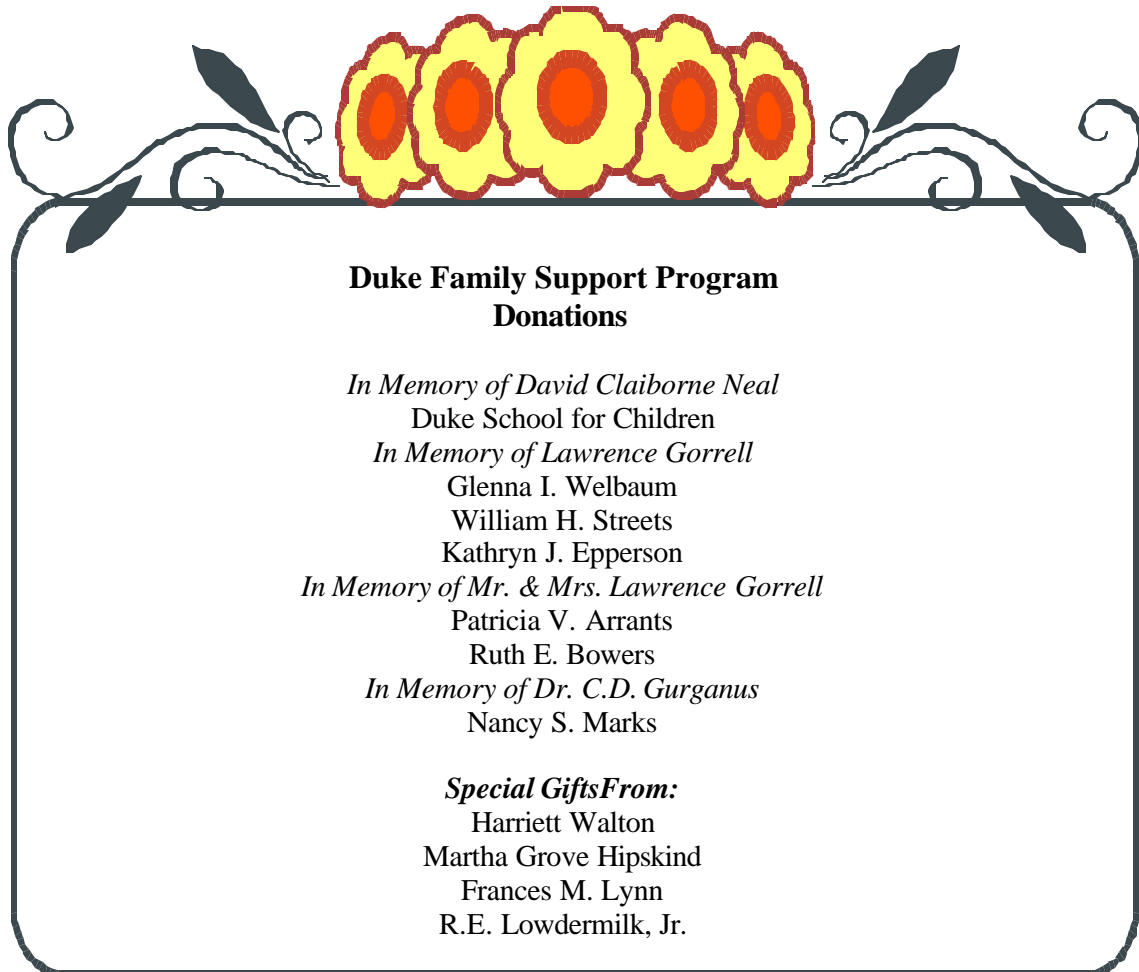
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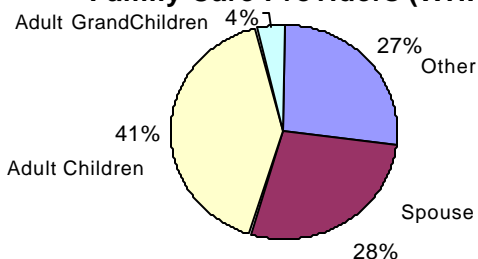
It is not the amount of the giving—
but in the giving.

Alex Port, 1911-

Caregiver for Sylvia, his wife of 68 years

Before her death in June, 2001.

Family Care Providers (WHITE)



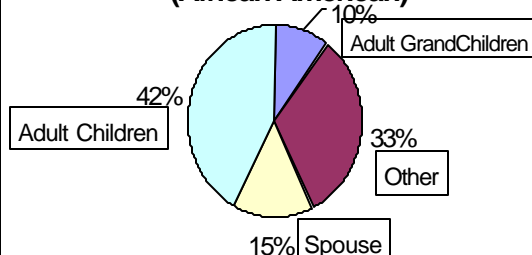
FAMILY CAREGIVING:
You are not alone...

Perception

What we see depends mainly
On what we look for.

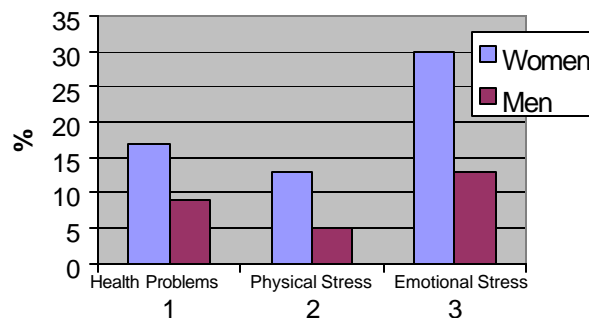
-John Lubbock

Family Care Providers (African American)

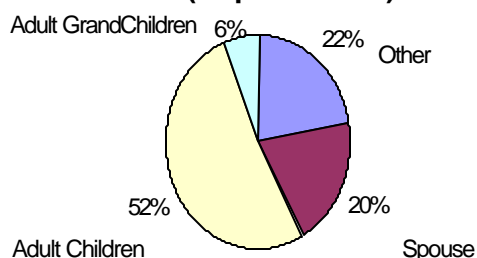


Percent of Caregivers Experiencing Stress

National Academy of Aging 1997



Family Care Providers (Hispanic/Latino)



National Academy of Aging 1993

Understanding

Home is not where you live,
But where they understand you

-Christina Morgenstern

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